

Wisconsin eHealth Care Quality and Patient Safety Board Consumer Interests Workgroup

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SUMMARY OF RECOMMENDATIONS

Accurate, understandable information is critical to high quality health care and improved population health. Electronic health records (EHR), health information technology (HIT), and health information exchange (HIE) provide opportunities to empower consumers and ensure robust patient data are available to providers at the point of treatment, dramatically improving both quality and efficiency of care. HIT and HIE also enable enhanced monitoring of the individuals and entities that access patient health information, serving as a double-check to patient privacy. As well, these technologies present opportunities to strengthen knowledge about disease, treatment, and effectiveness of health care. Some consumers have expressed concerns that patient information within EHRs and HIE will be misused. These recommendations reflect the Consumer Interests Workgroup's efforts to balance the benefits of HIT/HIE with privacy concerns to achieve optimal patient care.

Underlying Principles

The Consumer Interests Workgroup has adopted the principles below as the foundation for each charge listed in their charter. These principles were developed by the Markle Foundation's Personal Health Technology Council.

1. Individuals should be able to access their health and medical data conveniently and affordably.
2. Individuals should be able to designate someone else to have access to and exercise control over how their records are shared.
3. Individuals should receive easily understood information about all the ways that their health data may be used or shared.
4. Individuals should be able to review which entities have had access to their personal health data.
5. Electronic health data exchanges must protect the integrity, security, privacy, and confidentiality of an individual's information.
6. Independent bodies, accountable to the public, should oversee the electronic health data exchanges. No single stakeholder group should dominate these oversight bodies. Consumer representatives selected by their peers should participate as full voting members.

Actions and Recommendations

Charge 1: *Understand consumer expectations regarding electronic health data exchange.*

The workgroup undertook an extensive review of national surveys and literature capturing consumers' views of HIT, HIE, and EHR. In addition, the group organized a listening session for Wisconsin advocacy groups and consumers. These efforts captured consumer support for a transition from paper health records to EHR and HIT as well as concern about the privacy, security, and confidentiality of personal health information in an electronic environment. Privacy concerns were most notable for

more sensitive types of health information, particularly mental health and domestic violence. Research and discussion of consumer expectations set the stage for consideration of all other charges.

Charge 2: *Identify HIE and HIT outcomes that are highest priority from the consumer perspective.*

The Consumer Interests Workgroup identified the following outcomes as its highest priorities:

- Improved patient care through appropriate consumer and provider access to health information and evidence-based decision support.
- Privacy, security, and confidentiality of personal health information.
- Improved communication among all parties relevant to patient care.
- Improved consumer understanding of patient rights, responsibilities, and benefits associated with personal health information and health information exchange.
- Increased patient participation in decision-making regarding one's own health, health care, and health information.

The group also noted the importance of reliable and accurate identity verification mechanisms supporting health information exchange: poor identity matches can result in inadvertent disclosure of personal health information and substantially increase the risk of medical errors.

Charge 3: *Define acceptable and unacceptable data use policies to maintain privacy and security, including agreements for patient consent and use of data.*

- **Rec. 3.1:** Personal health information should be included in an exchange available to health care providers for treatment purposes; patients should not be able to opt-in to, or out of, this exchange.
- **Rec. 3.2:** Data use policies should: (1) balance patients' right to privacy with providers' need to access health information to provide optimal care; and (2) differentiate among the areas delineated by HIPAA (treatment, health care operations, payment, research, and public health).

Charge 4: *Make recommendations on whether health information with special protections will be included in electronic health data exchange.*

- **Rec. 4.1:** The Wisconsin legislature should amend Wisconsin law governing disclosure of health information to providers to be consistent with HIPAA, which does not require patient consent to disclose information to providers about mental health and developmental disabilities for treatment purposes. This recommendation:
 - Aims to improve providers' ability to give patients optimal care;
 - Increases Wisconsin's potential to participate in multi-state exchanges for treatment; and
 - Rests on the assumption that participating organizations have security measures that sufficiently protect all personal health information.

While this recommendation goes forward, it was not unanimously supported. Some workgroup members expressed concerns about stigma, potential bias in care, and patients withholding information to the detriment of their health and health care.

- **Rec. 4.2:** The Wisconsin legislature should review Wisconsin Statutes protecting patient rights and revise them as necessary to ensure that any provider or entity that provides unfair or inappropriately discriminatory treatment is subject to severe penalties.
- **Rec. 4.3:** The Wisconsin legislature should review Wisconsin Statutes protecting patient rights and revise them as necessary to ensure that any provider or entity that deliberately or inadvertently mishandles, inappropriately shares, or inappropriately distributes personal health information is subject to severe penalties. Penalties should reflect the egregiousness of the act.
- **Rec. 4.4:** Health information exchanges must protect the integrity, security, privacy, and confidentiality of all personal health information and recognize that some types of information are especially sensitive. Thus, organizations participating in exchange should consider appropriate *additional* technical and/or procedural safeguards for more sensitive types of health information.

Charge 5: *Define acceptable and unacceptable data use policies for oversight purposes, including public health and research.*

The recommendations below apply specifically to data used for public health and research purposes. Policies governing data use for other oversight purposes, (e.g., quality improvement, health care operations, safety initiatives, utilization review, etc.) should be discussed in the next phase of Wisconsin's eHealth Initiative.

- **Rec. 5.1:** Data use agreements and policies that support HIE should ensure that: (1) all reports and publicly available data sets resulting from provider-submitted identifiable data continue to include only de-identified data; and (2) strict controls continue to govern access to, and use of, reported data.
- **Rec. 5.2:** Designated public health entities should support and leverage new capabilities available through HIE and electronic reporting to improve the health of the public.
- **Rec. 5.3:** As new data sources emerge, policies governing access to health care data for research purposes should consider the original purpose of data collection, such as: data captured by providers at the point of care, held by an HIE, or collected explicitly for research purposes.

The group also noted that designated public health entities' ability to collect identified personal health information for statutorily mandated purposes will be enhanced as a result of HIE.

Charge 6: *Define guidelines and examples that clarify how data sharing can balance the requirement to protect privacy and security with the need to share information to improve care.*

Wisconsin's eHealth Initiative is in the process of identifying privacy and security policies and practices that may impact the exchange of health information as part of the national Health Information Security and Privacy Collaboration (HISPC) project. These activities will form the basis for the

selection of real-world examples that best demonstrate how data sharing can balance patient privacy and system security with the need to share information to improve patient care.

Charge 7: *Identify options to help consumers manage their own health care, advocate for themselves, and support mutual accountability for health.*

- **Rec. 7.1:** Holders of personal health information should ensure that individuals are able to conveniently and affordably access their health information, including which entities have had access to this information.
- **Rec. 7.2:** The state should undertake an education campaign that communicates the purpose, capabilities, and system safeguards of exchange as part of Wisconsin's eHealth Action Plan. Education materials and activities must be easily understandable and accessible for Wisconsin consumers regardless of health literacy, reading skill, computer proficiency, or geographic location. Materials and activities must appropriately address the language, educational, and cultural needs of consumers of all backgrounds (be culturally competent) and be easily accessible for all Wisconsin residents.
- **Rec. 7.3:** All relevant stakeholders should share financial responsibility (costs) and benefits (savings) affiliated with HIT and HIE.
- **Rec. 7.4:** Consumer representatives should have roles equal to those of other stakeholders in the ongoing governance of Wisconsin's HIE activities.
- **Rec. 7.5:** The state should raise consumer awareness of personal health records (PHRs) as a mechanism to manage one's health and health care.

Charge 8: *Identify legal actions required for the priorities recommended by the clinical work team.*

- **Rec. 8.1:** The Wisconsin legislature should amend Wisconsin law governing disclosure of health information to providers for treatment purposes to be consistent with HIPAA. (Charge #4)
- **Rec. 8.2:** The Wisconsin legislature should review Wisconsin Statutes protecting patient rights and revise them as necessary to ensure that any provider or entity that provides unfair or inappropriately discriminatory treatment is subject to severe penalties. (Charge #4)
- **Rec. 8.3:** The Wisconsin legislature should review Wisconsin Statutes protecting patient rights and revise them as necessary to ensure that any provider or entity that deliberately or inadvertently mishandles, inappropriately shares, or inappropriately distributes personal health information is subject to severe penalties. Penalties should reflect the egregiousness of the act. (Charge #4)
- **Rec. 8.4:** The Wisconsin legislature should amend law to support electronic reporting of health related data to statutorily identified entities. (Charge #5)

- **Rec. 8.5:** As Wisconsin's eHealth Initiative moves forward with the HISPC project and other eHealth activities, the eHealth Board should monitor potential impacts on Wisconsin Statutes and recommend changes as warranted.

Charge 9: *Fulfill responsibilities required by the state's contract with Research Triangle International (RTI) for the Health Information Security and Privacy Collaboration (HISPC).*

The first two phases of the HISPC project are complete. Two volunteer workgroups, *Variations* and *Legal*, reviewed scenarios designed by RTI and highlighted potential procedural and legal challenges to health information exchange. A number of Consumer Interests Workgroup members were active participants in both workgroups. Consumer Interests Workgroup members will continue to play an active role in the *Solutions* and *Implementation* phases of the HISPC project.

Next Steps

The Consumer Interests Workgroup has made significant progress towards each of its charges and has initiated dialogue with individual consumers and consumer groups. As Wisconsin advances towards adoption and implementation of interoperable electronic health records, it will be crucial for the eHealth Board to continue engaging consumers and their advocates in constructive, open discussions. The following activities should also be high priorities for the eHealth Board in the next stages of Wisconsin's eHealth Initiative:

1. Define specific recommended guidelines and real-world examples that clarify how data sharing can balance the requirement to protect patient privacy and system security with the need to share information to improve patient-centered care.
2. Develop recommendations for actions that will prevent breaches of privacy, security, or confidentiality of patient health information, within organizations and in the exchange of information among organizational systems, as well as remedies for any breaches that occur.
3. Develop specific mechanisms to accommodate patient concerns and complaints related to health information exchange.
4. Build understanding of, and support for, health information exchange among consumers and health care providers through education efforts.
5. Guide implementation of the consumer interests and privacy components of the eHealth Action Plan; assess and report on progress annually.
6. Develop policy statements and recommendations regarding use of health information for purposes other than treatment (e.g., patient safety initiatives, quality improvement, health care operations, payment, law enforcement, etc.).
7. Develop policy statements and recommendations that empower consumers to manage their health, health care, and health information.
8. Oversee preparation of final reports for the Health Information Security and Privacy Project.

BACKGROUND

Governor Jim Doyle created the eHealth Care Quality and Patient Safety Board by Executive Order 129 on November 2, 2005. The eHealth Board is charged with developing the Wisconsin *eHealth Action Plan*, Wisconsin's five-year action plan for the adoption and exchange of interoperable electronic health records. Five workgroups guide development of this plan: Patient Care, Information Exchange, Consumer Interests, Governance, and Financing.

The Consumer Interests Workgroup is particularly concerned with assuring that Wisconsin's eHealth Action Plan reflects the needs, desires, and concerns of consumers. In this context, consumers are defined as: individuals receiving care or helping to provide, manage, or monitor the care of a family member or others.

The Consumer Interests Workgroup is charged with the following:

- Developing recommendations for serving consumer health information needs;
- Addressing issues of privacy and security, in both the use of electronic health records and the exchange of information among multiple systems or providers;
- Understanding consumer expectations regarding the electronic exchange of health data;
- Identifying desired outcomes and options so that consumers are well prepared to manage their own health care and advocate for themselves as they use health care services; and
- Ensuring that initiatives are customer-focused.

This document outlines the Consumer Interests Workgroup's recommendations pertaining to each specific charge in the group's charter.

INTRODUCTION

Accurate, understandable information is critical to high quality health care and improved population health. Electronic health records (EHR), health information technology (HIT), and health information exchange (HIE) provide opportunities to empower consumers and ensure robust patient data are available to providers at the point of treatment, improving both quality and efficiency of care. HIT and HIE also enable enhanced monitoring of the individuals and entities that access patient health information, serving as a double-check to patient privacy.^{1,2} As well, these

¹ For a more complete discussion of the differences between paper and electronic health records, see pages 146-147 of Randolph C. Barrows, Jr. MD and Paul D. Clayton PhD, "Privacy, Confidentiality and Electronic Medical Records." Journal of the American Medical Informatics Association. Vol. 3 No. 2: (March/April 1996). Online at: <http://www.jamia.org/cgi/reprint/3/2/139.pdf> (accessed 11/20/06).

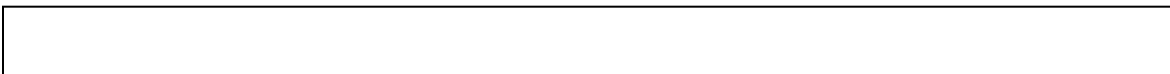
² For a detailed discussion of audit logs in an electronic environment, see Connecting For Health Common Framework's 'Auditing Access to and Use of a Health Information Exchange:' http://www.connectingforhealth.org/commonframework/docs/P7_Auditing_Access.pdf (accessed 11/17/06).

technologies present opportunities to strengthen knowledge about disease, treatment, and effectiveness of health care. Some consumers are concerned that these technologies will expand access to their personal health information and increase the likelihood that this information will be misused.

Most health information exchanges, statewide eHealth initiatives, and other entities planning such an effort have worked to balance consumers' ability to control their health information with providers' need to access this information to provide optimal care. Wisconsin's Consumer Interests Workgroup looked to national experts to help inform their consideration of these issues. The workgroup adopted principles developed by the Markle Foundation's Personal Health Technology Council (below) as the foundation of the more detailed recommendations that follow in the body of this report.³

1. Individuals should be able to access their health and medical data conveniently and affordably.
2. Individuals should be able to designate someone else to have access to and exercise control over how their records are shared.
3. Individuals should receive easily understood information about all the ways that their health data may be used or shared.
4. Individuals should be able to review which entities have had access to their personal health data.
5. Electronic health data exchanges must protect the integrity, security, privacy, and confidentiality of an individual's information.
6. Independent bodies, accountable to the public, should oversee the electronic health data exchanges. No single stakeholder group should dominate these oversight bodies. Consumer representatives selected by their peers should participate as full voting members.⁴

ACTIONS AND RECOMMENDATIONS



To gain a balanced understanding of consumer expectations, the group looked to surveys capturing consumer views of electronic health records, health information technology, and health information

³ According to its web site, "The Personal Health Technology Council identifies and recommends solutions for policy challenges affecting the adoption of personal health records and related technologies with a sharp focus on the needs and concerns of consumers." For more information, see: <http://connectingforhealth.org/phti/index.html> (accessed 10/6/06).

⁴ With the exception of principle number two, these statements are taken directly from the Markle Foundation's Personal Health Technology Council "Consumer and Patient Principles for System Design." In the Markle Principles, statement number two reads: "Individuals should be able to designate someone else, such as a loved one, to have access to and exercise control over how their records are shared." For more, see: http://www.markle.org/downloadable_assets/consumer_principles_101105.pdf (accessed 9/26/06).

exchange. In addition, the group reviewed numerous articles discussing the risks and benefits of these technologies from the perspective of health care consumers and patients. And, the workgroup organized a Consumer Listening session for Wisconsin advocacy groups and consumers in September 2006. Extensive discussions of the perspectives gleaned from these efforts set the stage for consideration of all other charges.

1.1 National Survey Findings

An October 2005 survey conducted on behalf of the Markle Foundation and a November 2005 survey conducted on behalf of the California Healthcare Foundation found strong support for electronic health records and a national health information network as well as significant concerns about the privacy and security of personal health information.^{5,6} The Markle Foundation survey reports that more than seven out of ten Americans support the creation of a nationwide health information exchange or network for doctors and patients.⁷ In addition, six out of ten Americans (60%) support the creation of a secure online personal health record (PHR) service that allows consumers to: check and refill prescriptions; get results over the Internet; check for mistakes in an individual's own medical record; and conduct secure and private e-mail communication with an individual's doctor or doctors.⁸ Further, an earlier (2003) Markle Foundation report suggests that consumers will *use* such a service:

- 63 percent would track immunizations;
- 63 percent would look up and track their own test results;
- 69 percent would monitor their record mistakes;
- 65 percent would transfer information to new doctors; and
- 75 percent say they would e-mail their doctor.⁹

The California Healthcare Foundation survey, however, reports substantial patient concerns about privacy: 67 percent of survey respondents are "concerned" or "very concerned" about the privacy of their personal medical records.¹⁰ Other survey findings include:

⁵ Public Opinion Strategies for the Markle Foundation, "Attitudes of Americans Regarding Personal Health Records and Nationwide Electronic Health Information Exchange: Key Findings from Two Surveys of Americans." (10/05): http://www.phrconference.org/assets/research_release_101105.pdf (accessed 9/26/06).

⁶ Forrester Research, Inc. for the California Healthcare Foundation, "National Consumer Health Privacy Survey 2005." (11/05): <http://www.chcf.org/topics/view.cfm?itemID=115694> (accessed 9/26/05).

⁷ For the Markle survey, respondents were read the following statement describing health information exchange: "Now let's imagine that a nationwide health information exchange or network were set up for doctors and patients. Access to the information would be controlled in secure online accounts. Only with the patient's permission could their medical information be shared through this network. The patient would control what information from their medical records is made available to other physicians. In an emergency situation, a patient's information could only be accessed with the permission of an authorized family member or representative. The medical information of a patient who participates in the nationwide information exchange would not be in one central database, but would continue to be held and maintained by their doctors or health care providers." For more information, see: Public Opinion Strategies for the Markle Foundation (10/05).

⁸ Ibid.

⁹ Connecting for Health Collaborative. The Personal Health Working Group: Final Report. Markle Foundation (7/1/03): http://www.connectingforhealth.org/resources/final_phwg_report1.pdf (accessed 10/11/06).

¹⁰ Forrester Research, Inc. for the California Healthcare Foundation, <http://www.chcf.org/topics/view.cfm?itemID=115694>

- One in eight patients reportedly engages in behavior to protect personal privacy (e.g., asking a doctor to ‘fudge’ a diagnosis, paying for a test to avoid submitting a claim, or avoiding their regular doctor) that presents a potential risk to their health.
- More than half (52 percent) of respondents are concerned that employers may use health information to limit job opportunities.¹¹

Appropriately balancing these perspectives—and gaining external stakeholder input to do so—was identified early as a critical role for the Consumer Interests Workgroup.

1.2 Stakeholder Listening Session

The workgroup’s September 12, 2006, listening session held in Oconomowoc, Wisconsin attracted nearly 70 participants. In addition, almost a dozen individuals joined the session online through the Department of Health and Family Services (DHFS) Mediasite™ broadcasting tool. Attendees represented mental health and substance abuse treatment providers, domestic violence advocates, American Indian health services, health care providers, payers, genetic counselors, and other individuals and organizations interested in sharing opinions about Wisconsin’s eHealth Initiative.

During this event, attendees were invited to share thoughts and concerns on behalf of themselves, their clients, constituencies, and communities about the adoption of electronic health records and health information technology. In addition, the workgroup considered written comments collected onsite and submitted online and via U.S. mail during the weeks following the event. The following themes were most prevalent:

- Patients should have access to their own health information.
- Designated providers should have access to a patient’s health information without a patient’s consent for treatment purposes in most circumstances.
- Access to personal health information and electronic health records must be carefully controlled to prevent misuse and loss of privacy.
- There is significant concern about access to more sensitive health information (e.g., treatment for mental health, domestic abuse, alcohol and drug abuse, etc.) by general treatment providers without patient consent.
- Proposed policies regarding access to more sensitive health information should be careful, deliberate, and transparent and should address possible consequences of each given proposal (e.g., patient concealment of sensitive health information, abuser access to victim records, etc.).
- Anti-discrimination legislation, provider education, and severe consequences for failing to adhere to privacy policies are three possible mechanisms of addressing concerns regarding more sensitive information.

¹¹ Ibid.

- Remedies and consequences for breaches of patient privacy, security, and confidentiality are critical elements of health information exchange.
- The regulations governing schools' roles and responsibilities as health care providers (FERPA) should be considered in conjunction with discussions of the regulations regarding information exchange among other providers for treatment purposes (HIPAA).
- It is important to educate consumers regarding: the nature of health information exchange; how an individual can access his or her own health information; and who else can access that information under what circumstances.
- Policy, not current technology capability, should drive workgroup recommendations.

The input received during this session proved invaluable to the workgroup's contributions to Wisconsin's *eHealth Action Plan*. It also highlighted the importance of continued outreach and education of consumers and providers as Wisconsin transitions from paper health records to electronic health records and health information exchange. Recommendations regarding the content of ongoing education efforts are discussed under Charge #7 of this report.

CHARGE 2: Identify health information exchange (HIE) and health information technology (HIT) outcomes that are highest priority from the consumer perspective.

Health information technology and health information exchange hold promise as a means of improving quality, increasing efficiency, and reducing the cost of health care. During his keynote address at the eHealth Initiative (eHI) Third Health Information Technology Summit, for example, former Health and Human Services Secretary Mike Leavitt asserted: "we have the opportunity with interoperable health information technology to dependably measure price and quality in healthcare. That adds up to value and is critical to changing America's healthcare system."¹²

States are embracing this opportunity. The eHealth Initiative reports that 38 state legislatures have introduced 121 bills focusing specifically on HIT in 2005 and 2006; during this time, 36 such bills were passed in 24 states.¹³ In addition, 10 state Governors issued Executive Orders "calling for the development of strategies, plans, and recommendations for using HIT and health information exchange to improve health and health care," and numerous state plans were initiated.¹⁴ Arizona's Health-e Connection Roadmap is one such plan. According to the Arizona roadmap:

"A statewide infrastructure to exchange health information electronically will improve the quality and reduce the cost of healthcare in Arizona by:

¹² National, State Healthcare Leaders in the Spotlight at eHI's Third Health Information Technology Summit, Press Release. (9/26/06): <http://www.ehealthinitiative.org/default.aspx> (accessed 9/27/06).

¹³ eHealth Initiative and Foundation Issue Brief, "States Getting Connected: State Policy-Makers Drive Improvements in Healthcare Quality and Safety Through IT." (8/06): <http://www.ehealthinitiative.org/assets/documents/StateReportIssueBrief-08.31.06FINAL1.pdf> (accessed 9/27/06).

¹⁴ Ibid.

- Ensuring health information is available at the point of care for all patients;
- Reducing medical errors to improve patient safety;
- Avoiding duplicative medical procedures;
- Improving coordination of care between hospitals, physicians, and other healthcare professionals;
- Furthering healthcare research;
- Enhancing public health and disease surveillance efforts;
- Encouraging greater consumer participation in their personal healthcare decisions; and
- Enhancing the business environment for both small and large employers and reducing state expenditures by controlling healthcare costs.”¹⁵

Private organizations, too, see great possibility in health information technology and health information exchange. At the 2004 OECD Health of Nations Forum, for example, former AARP president Marie Smith asserted: “I believe ehealth can bring us to a point where our consumers of health care and medical services have the information they need to participate to a far greater extent in their own care—and to make intelligent, informed decisions about the doctors and hospitals they use, and about which courses of treatment they should follow.”¹⁶

The Consumer Interests Workgroup considered these and other possible outcomes of health information technology and health information exchange, identifying those outcomes that could provide the greatest benefit to consumers. In addition, the group considered the data elements identified by the Patient Care Workgroup of the eHealth Board as short-term priorities for a Wisconsin exchange in order to: (1) identify data elements that present heightened risks to patient privacy; and (2) support improvements in patient care. These discussions were informed by a review of statutes governing the disclosure of personal health information in Wisconsin for treatment purposes.¹⁷

2.1 High Priority Outcomes of HIE and HIT

The Consumer Interests Workgroup identified the following outcomes as its highest priorities in Wisconsin’s transition from paper records to electronic records and health information exchange:

- Improved patient care through appropriate consumer and provider access to health information and evidence-based decision support.
- Privacy, security, and confidentiality of personal health information.
- Improved communication among all parties relevant to patient care.

¹⁵ Arizona Health-e Connection Roadmap. (4/4/06): http://gita.state.az.us/tech_news/2006/Arizona%20Health-e%20Connection%20Roadmap.pdf (accessed 9/27/06).

¹⁶ Global Aging Program Speeches, eHealth: Roadmap for 21st Century Health Care Consumers. Marie F. Smith AARP President at OECD Forum 2004 “Health of Nations.”(2004): <http://www.aarp.org/research/international/speeches/a2004-05-19-smithoecdremarks.html> (accessed 11/17/06).

¹⁷ This review, conducted by the workgroup’s privacy experts, focused on regulations governing the disclosure of more sensitive types of personal health information. See Appendix A for the group’s summary.

- Improved consumer understanding of patient rights, responsibilities, and benefits associated with personal health information and health information exchange.
- Increased patient participation in decision-making regarding one's own health, health care, and health information.

2.2 Patient Care Workgroup Priorities for HIE

The eHealth Board's Patient Care Workgroup identified a summary view of current and historical patient information from all sources of care as a top priority during the five-year horizon of Wisconsin's eHealth Action Plan.¹⁸ The table below lists the data elements the Patient Care Workgroup gave the highest priority for inclusion in this summary, as well as elements the Consumer Interests Workgroup identified as priorities and heightened privacy concerns.

Patient Care Priority Data Elements	Consumer Interests Priority	Heightened Privacy Concern
Identity/demographics	√	√
Diagnoses/encounter diagnoses	√	√
Medications	√	√
Allergies	√	√
Labs/other diagnostics (results reporting)	√	√
Procedures	√	√
Immunizations	√	
Patient visits and hospitalizations	√	√
Discharge summaries/progress notes	√	√
Patient contact-in-emergency		
Advance directives		
Payer/insurance coverage/eligibility		√
Medical devices (see 2.3 below)	√	

The Consumer Interests Workgroup stressed that data elements necessary for direct patient care should be considered the highest priorities for inclusion in a summary view of patient information. It is imperative that each of the data elements above be stringently protected; however, the elements listed as 'heightened privacy concerns' have the greatest potential to cause harm if disclosed inappropriately.

The group also emphasized the importance of reliable and accurate identity verification mechanisms in health information exchange efforts. Poor identity matches can result in inadvertent disclosure of personal health information and substantially increase the risk of medical errors.

¹⁸ The full report of the Patient Care Workgroup is available on the eHealth Board web site: <http://ehealthboard.dhfs.wisconsin.gov/> (accessed 10/30/06).

2.3 Patient Care Workgroup Priorities for HIE: Suggested Additions

To support comprehensive, continuous care, the group suggests adding ‘medical devices’ such as pacemakers, hearing aids, and implants to the high priority EHR/HIE data elements identified by the Patient Care Workgroup. In addition, the group recommends consulting emerging standards for the continuity of care record.¹⁹

CHARGE 3: Define acceptable and unacceptable data use policies to maintain privacy and security including agreements for patient consent and use of data, including: (1) Whether patients will be permitted to opt-out of having their information in the exchange; and (2) How patients will access their own data.

Privacy, security, and confidentiality of patient health information are principal concerns in discussions of health information technology and health information exchange. Some consumers have expressed concern that electronic health records and exchange will expand access to their personal health information and increase the likelihood that this information will be misused—with negative ramifications on insurance status, employment, privacy rights, family life, and/or quality of health care.^{20,21,22,23,24}

User management systems, data use agreements, and patient consent requirements are three commonly discussed mechanisms of addressing these concerns. User management systems set and enforce policies for access to personal health information based on organizational and individual roles and/or rules. Data use agreements outline acceptable uses for information exchanged.²⁵ And, patient consent requirements allow patients to limit access to, and use of, their health information.

Patient consent can be broad reaching (i.e., all care by a certain provider or provider system) or very specific in scope (i.e., pertaining to a specific treatment only). In the context of health information exchange, patient consent is generally discussed in two forms: (1) opt-in, which requires a patient to choose to participate in an exchange; and (2) opt-out, which allows a patient to choose not to have his or her information included in the exchange.²⁶ Operating health information exchanges, statewide

¹⁹ For more information about the Continuity of Care Record, see: <http://www.continuityofcarerecord.org/x6169.xml> (accessed 9/28/06).

²⁰ Los Angeles Times. “At risk of exposure: In the push for electronic medical records, concern is growing about how well privacy can be safeguarded.” (6/26/06).

²¹ Emily Friedman, “Privacy? What Privacy? Confidentiality Who?” HospitalConnect.com (5/14/06): http://www.hhnmag.com/hhnmag/hospitalconnect/search/article.jsp?dcrpath=HHNMAG/PubsNewsArticle/data/2006June/060606HHN_Online_Friedman&domain=HHNMAG (accessed 9/27/06).

²² Ricardo Alonso-Zaldivar, “Bill Seeks National Medical Records System: Congress wants all patients' data to be computerized. But critics say the legislation needs more privacy safeguards, pointing to recent breaches.” Los Angeles Times (8/13/06).

²³ Health Privacy Project, <http://www.healthprivacy.org/> (accessed 10/30/06).

²⁴ Patient Privacy Rights, <http://www.patientprivacyrights.org/site/PageServer> (accessed 10/30/06).

²⁵ For an example of a data use agreement pertaining to health information exchange, see: Christopher S. Sears, Esq. et al, The Indiana Network for Patient Care: A Case Study of a Successful Healthcare Data Sharing Agreement. (2005): <http://www.abanet.org/health/esource/vol2no1/Sears.pdf> (accessed 9/28/06).

²⁶ For a discussion of the ethics of opt-in and as compared to opt-out, see Ole Frithjof Norheim, Soft Paternalism and the Ethics of Shared Electronic Patient Records: It's Ethically Sound for Patients To Opt-out. (6/23/06): <http://bmj.bmjournals.com/cgi/content/full/333/7557/2?ehom> (accessed 9/28/06).

initiatives, and other bodies considering such efforts have taken a variety of approaches to the issue of patient consent.²⁷

3.1 Data Use Policy Considerations

Regulations governing access to personal health information currently hinge on two key factors: who uses health information, and for what purpose. The workgroup agreed that these factors should continue to steer data use and consent requirements in an electronic environment. More specifically, ongoing and future discussions of data use policies should differentiate among the areas delineated by HIPAA: treatment, health care operations, payment, research, and public health.

3.2 Consent Requirements (Opt-in, Opt-out, or ‘No Opt’)

Under Wisconsin law, sharing health information generally takes precedence over privacy when information is shared among health care providers for treatment purposes. In cases of treatment for mental health, developmental disability, and alcohol/other drug abuse, however, personal health information is generally shared only with explicit patient consent.²⁸ Wisconsin’s patient consent requirements for mental health and developmental disability are more stringent than federal HIPAA regulations.²⁹

Consistent with current law, the workgroup recommends that personal health information be included in a Wisconsin health information exchange available to health care providers for treatment purposes. Patients should not be able to opt-in to or opt-out of this exchange.

Concerns about inappropriate access and use of personal health information are greatest for more sensitive types of personal health information (e.g., mental health, alcohol and drug abuse treatment, communicable diseases, and genetic testing). Some attendees at the September Consumer Interests Listening Session emphasized this point. According to one individual, for example, “[mental illness] stigma is, unfortunately, alive and well, and as long as it is, it is not unreasonable for a person with a mental illness to be reluctant to have that information shared.” Another attendee, representing the

²⁷ The Markle Foundation and the Health Privacy Project, for example, have endorsed ‘opt-out’ statements while the state of Maine’s Consumer Stakeholder Committee has endorsed an ‘opt-in’ position for its HealthInfoNet. For more information, see each organization’s consumer principles: http://www.markle.org/downloadable_assets/consumer_principles_101105.pdf (Markle); http://www.healthprivacy.org/usr_doc/HIT_-_Consumer_Principles.pdf Health Privacy Project; http://www.hinfonyet.org/meetings/ConsumerPrinciples_20051207.doc (Maine). (Each accessed 10/5/06).

²⁸ Per WI 51.30

²⁹ For a summary of the differences between HIPAA and Wisconsin Statute as they apply to developmental disabilities and mental health, see Appendix B.

concerns of victims of domestic violence, referenced the balance between the risk of sharing information and the risk of inadequate provider information, asserting: “risk assessment should be discussed with the patient and the final decision [re: information sharing] should be up to the patient.”

These concerns exist in tandem with concerns about the ramifications of *not* including more sensitive types of health information in an exchange intended for health care treatment providers. Will excluding this information from exchange negatively impact patient care? That is, can physicians provide patients with the best possible care without full knowledge of their condition(s) and medication(s)? How can Wisconsin participate in cross-state and national health information exchange with consent requirements that differ from HIPAA regulations? And, will requirements to segment health information create a burden on health care providers that obstructs exchange?

4.1 Assumptions

The recommendations that follow apply to **health information available to providers for treatment purposes** and rest on the following assumptions:

- Health care providers will exchange health information for treatment purposes only.³⁰
- As a condition of participating in exchange, organizations will have adequate *technical/electronic* security measures to ensure appropriate access to health information.
- As a condition of participating in exchange, organizations will have adequate *procedural* security measures to ensure appropriate access to health information.

Recommendations regarding the use of personal health information for research and public health purposes are outlined under charge #5. Recommendations regarding use of this information for other purposes (payment, health care operations, etc.) should be considered in the next phase of Wisconsin’s eHealth Initiative.

4.2 Safeguards for Privacy, Security, and Confidentiality

Health information exchanges must protect the integrity, security, privacy, and confidentiality of all personal health information and recognize that some types of information are especially sensitive. Thus, the workgroup recommends that all organizations participating in exchange implement appropriate additional technical and/or procedural safeguards for more sensitive types of health information, such as:

- Mental health
- Alcohol and drug abuse treatment
- Communicable disease (including HIV/AIDs)
- Genetic testing

³⁰ For a definition of ‘health care provider’ see Appendix C.

- Adoption
- Developmental disabilities
- Sexual assault
- Domestic violence

As Wisconsin moves towards adoption and implementation of electronic health records and health information exchange, it will be crucial for the eHealth Board to continue meaningful dialogue with these stakeholders to reach a shared understanding of ‘appropriate safeguards.’

4.3 Information Included in Exchange

The Wisconsin legislature should amend Wisconsin law governing disclosure of health information to providers for treatment purposes to be consistent with HIPAA. This proposed change would remove the requirement to obtain patient consent to disclose information about mental health and developmental disabilities to providers for treatment purposes.³¹

In conjunction with this recommendation, the Wisconsin legislature should:

- Review Wisconsin Statutes protecting patient rights and revise them as necessary to ensure that any provider or entity that provides unfair or inappropriately discriminatory treatment is subject to severe penalties.
- Review Wisconsin Statutes protecting patient rights and revise them as necessary to ensure that any provider or entity that deliberately or inadvertently mishandles, inappropriately shares, or inappropriately distributes personal health information is subject to severe penalties. Penalties should reflect the egregiousness of the act.

These recommendations are intended primarily to improve patient care by giving providers full information to assess patient health and provide treatment. In addition, they aim to increase Wisconsin providers’ potential to participate in national and cross-state information exchange for treatment purposes in a manner that protects the privacy and security of personal health information.

4.4 Concerns

This recommendation was supported by the large majority of, but not all, workgroup members. Echoing comments from attendees at the September 12 Consumer Listening Session, some workgroup members voiced concern that sharing some types of sensitive information (e.g., mental health treatment) could create a bias in care and treatment to the detriment of the patient. Others noted that making all personal health information available to every provider could make patients less likely to share some types of information (e.g., alcohol and other drug use) or simply avoid seeking needed care. Last, it was noted that changing existing protections for health information could amplify consumer concerns about electronic health records and health information exchange.

³¹ Under 42 CFR Part 2, consent would still be required to disclose information pertaining to alcohol/drug abuse treatment.

CHARGE 5: Define acceptable and unacceptable data use policies for oversight purposes, including: (1) public health; and (2) research.

Clinical data available through electronic health records and health information technology hold promise for advancements in public health and research as well as direct patient care. According to a recent report by the American Medical Informatics Association, for example:

...use of health data can enhance health care experiences for individuals, expand knowledge about disease and appropriate treatments, strengthen understanding about the effectiveness and efficiency of our health care systems, support public health and security goals, and aid businesses in meeting the needs of their customers.³²

Access to more and different types of aggregated data also pose concerns about the privacy and confidentiality of personal health information. Thus, policies governing access to data must be carefully considered and balanced with privacy rights.

5.1 Data Use Value Statements

The workgroup adopted the following statements supporting responsible, controlled use of clinical data for public health and research purposes:

- Appropriate use of aggregate information about entire populations can facilitate advances in treatment, research, and public health that are not feasible under today's system.
- Electronic submission of mandated health-related information to statutorily designated entities, and sharing of this information as statute allows, can improve care for individual patients and Wisconsin's population as a whole.

5.2 Collecting Data for Public Health Purposes

Under Wisconsin law, health care providers are required to report certain events, diseases, and situations to statutorily identified public health agencies.³³ In addition, these agencies have authority to conduct surveillance, such as: analyzing trends in disease, maternal and child health, and other health hazards, or collecting data to investigate the cause/circumstance of special or unusual disease or mortality.³⁴

The workgroup agreed that current mandatory and discretionary reporting requirements for public health should not be altered as a result of health information exchange or electronic reporting capabilities, nor should designated public health entities' statutory authority to conduct surveillance.

³² Charles Safran, MD, MS, et al for the American Medical Informatics Association, "Toward a National Framework for the Secondary Use of Health Data. (9/14/06: pg. 3): <http://www.amia.org/inside/initiatives/healthdata.asp>. (accessed 9/26/06).

³³ For examples of Wisconsin's mandatory and discretionary reporting requirements, see Appendix D.

³⁴ For more information on designated public health entity's authority to conduct surveillance, see Appendix E.

Further, the group recommends no changes to existing policies governing disclosure of more sensitive health information for public health purposes.³⁵

5.3 Using Data for Public Health Purposes

State and local public health departments currently have data use agreements and security policies governing the re-disclosure of available data. With the advent of electronic provider reporting and health information exchange, these agreements and policies should be maintained and updated as necessary to support the recommendations below:

- Although providers submit identifiable data to public health entities, all reports and publicly available data sets resulting from such data should continue to include only de-identified data.
- Strict controls should continue to govern access to, and use of, reported data. Controls should:
 - identify legitimate purposes for access and use;
 - be enforced by data use agreements and knowledgeable data stewards; and
 - outline penalties for misuse.
- Existing public health oversight bodies should proactively seek out emerging data sources (e.g., ER data) and encourage responsible use that benefits public health.
- Designated state and local public health entities should coordinate access to relevant data with other entities active in public health efforts (e.g., DNR's Clean Water activities, etc.).

In addition, the legislature should amend Wisconsin law to support electronic reporting (e.g., as technology is available to facilitate electronic reporting, providers should move swiftly to adopt it and public health entities to receive information in electronic format). Moreover, the State should investigate and support incentives (financial or other) to encourage provider adoption and use.

5.4 Using Data for Research Purposes

Under current law, researchers can obtain identifiable health information for analysis with patient consent or with a waiver of the need for consent by an Institutional Review Board (IRB). The workgroup recommends no changes to existing policies governing disclosure of personal health information for research purposes.³⁶ However, health information exchange capability will introduce data sources that are not clearly addressed by existing policies. Thus, the workgroup recommends the following guidelines for future policy development:

- If data are collected specifically for research purposes, consumers should be allowed to choose to opt-in or opt-out and use should be limited to the entities and purposes outlined in the statement of consent and IRB application.

³⁵ For state and federal statutes governing disclosure of health information for public health purposes, see Appendix F.

³⁶ For state and federal statutes governing disclosure of health information for research purposes, see Appendix G.

- If data held by specific providers or exchanges are requested for research purposes, standards for consent and access should be consistent with organizational policies and state and federal regulations.

5.5 Data Disclosure for Other Purposes

Policies governing disclosure of health information for other purposes, including but not limited to: quality improvement, health care operations, safety initiatives, and utilization review should be considered in the next phase of Wisconsin's eHealth Initiative. These activities may occur in conjunction with the Health Information Security and Privacy Collaboration (HISPC) project (discussed in more depth under Charges #6 and #9). In addition, the eHealth Board should continue to guide oversight and study of disclosure policies as Wisconsin moves towards health information exchange.

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6.1 Guidelines and Real-World Examples

Wisconsin's eHealth Initiative is in the process of identifying privacy and security policies and practices that may impact the exchange of health information as part of the national Health Information Security and Privacy Collaboration (HISPC) project. This project includes a detailed examination of the policies and practices governing the exchange of health information in a number of specific scenarios, identification of possible barriers to exchange, and development of solutions to address identified barriers. These activities will form the basis for the selection of real-world examples that best demonstrate how data sharing can balance patient privacy and system security with the need to share information to improve patient care. Thus, this charge should be completed in conjunction with the HISPC project (anticipated completion April 2007). For additional information about the HISPC project, see Charge #9.

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How will the roles of consumers and patients change as providers and health systems move towards health information exchange and health information technology? What steps should be taken to better prepare all consumers for the changes that are coming? Already, many consumers are becoming more active stewards of their own care, seeking guidance about diagnosis, treatment, and

general health through the Internet and communicating with providers via secure Internet portals.³⁷ As a recent report from the California Healthcare Foundation cautions, however, “availability of information does not necessarily translate into understanding or taking appropriate actions.”³⁸ The recommendations below are intended to guide continued discussions of consumer rights, responsibilities, needs, and benefits related to a Wisconsin health information exchange.

7.1 Patient Access to Own Health Information

Individuals should be able to access their health/medical data, including which entities have had access to this information, conveniently and affordably. More specifically,

- Individuals should not bear unreasonable costs to access their health and medical data.
- Access should be available in a manner that does not unduly disadvantage those without ready Internet access.³⁹

7.2 Patient Education

One attendee at the September 12 Consumer Interests Listening session asserted that “consumers respond to the perception of security, privacy, and confidentiality regardless of the actuality of those aspects.” Thus, the workgroup recommends that the state, under the leadership of the eHealth Board, undertake a broad education campaign that communicates the purpose, capabilities, and system safeguards of health information exchange in Wisconsin. This patient education campaign should build understanding of, and support for, health information exchange in Wisconsin by:

- Communicating benefits of health information exchange, including: consumer empowerment; reduced drug interactions; new public health and research capabilities; improved health outcomes; increased availability and portability of health information; new opportunities for patient-provider interaction; and added system safeguards.⁴⁰

³⁷ For further discussion, see: Marc Siegel, “Who’s in Charge? It’s Your Care. Take Control of it, Recommends One Physician.” Washingtonpost.com (7/11/06).

³⁸ Joshua Seidman PhD, “Lost in Translation: Consumer Health Information in an ‘Interoperable’ World.” California HealthCare Foundation Issue Brief (9/05): <http://www.chcf.org/documents/ihealth/LostInTranslationIssueBrief.pdf> (accessed 10/10/06).

³⁹ These principles are informed by the Markle Foundation’s Personal Health Technology Council “Consumer and Patient Principles for System Design.” (10/05): http://www.markle.org/downloadable_assets/consumer_principles_101105.pdf (accessed 9/26/06).

⁴⁰ For an example of possible messages of such a campaign, see the consumer benefit statements included in the June 29, 2006 Minnesota e-Health Initiative Advisory Committee Emerging Themes and Preliminary Recommendations for Action Report (p. 4). Available online at: <http://www.health.state.mn.us/e-health/summit/recommendations06.pdf> (accessed 10/30/06).

- Addressing patient concerns about security, privacy, and confidentiality of health information exchange; and
- Increasing consumer's knowledge of their rights, including privacy rights, avenues for complaint resolution, and how to access one's own medical record.⁴¹

To build consumer trust and understanding, careful consideration should be given to how this information is shared. Education materials must be worded at a sixth-grade level, be available in multiple languages, and in alternative formats (i.e., non-written). Additional education efforts will be necessary for those disadvantaged by inadequate reading skills (below sixth-grade level), language barriers, low levels of health literacy, or computer proficiency.⁴² As well, education activities must appropriately address the language, educational, and cultural needs of consumers of all backgrounds (be culturally competent) and be easily accessible for all Wisconsin residents.

7.3 Provider Education

To maximize consumer benefits affiliated with a transition to electronic health records and health information exchange, providers must understand patients' perspectives on this transition. Thus, the state, in partnership with appropriate trade and professional associations, should undertake a provider education campaign in conjunction with the consumer-focused campaign discussed under section 7.2. This campaign should focus on increasing providers' understanding of patient concerns about, and benefits from, electronic health records and health information exchange.

7.4 Mutual Accountability for Health: Financing

All relevant stakeholders should share the financial responsibility (costs) and benefits (savings) affiliated with health information technology and health information exchange. Stakeholders include, but are not limited to: consumers, health care providers, physician practices/clinics, hospitals and other facilities providing health care services (e.g., nursing homes, hospice, etc.), health plans and other insurers, employers and government entities.

7.5 Mutual Accountability for Health: Governance

Consumers should have a strong role in the ongoing governance of Wisconsin's electronic health information exchange. Consumer roles and responsibilities in both the highest level of governance (i.e., the eHealth Board) and advisory councils should equal the roles of other stakeholders. No

⁴¹ A number of resources exist to guide communications in this area. For an example of such a resource, see: Joy Pritts JD and Nina L. Kudzus, Health Policy Institute Georgetown University, "Your Medical Record Rights in Wisconsin: A Guide to Consumer Rights under HIPAA." (2005): <http://hpi.georgetown.edu/privacy/records.html> (accessed 10/30/06).

⁴² A recent national study of health literacy found that "the majority of adults (53 percent) had Intermediate health literacy. An additional 12 percent of adults had Proficient health literacy. Among the remaining adults, 22 percent had Basic health literacy, and 14 percent had Below Basic health literacy." For further discussion of health literacy rates, see Mark Kutner et al, The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (NCES 2006-483) U.S. Department of Education. Washington, DC: National Center for Education Statistics. (2006)

single stakeholder group should dominate these oversight bodies.⁴³ Governance and administration of such a system must be transparent, accountable, and publicly available.

7.6 Personal Health Records

Personal health records (PHRs) empower consumers to manage their own health information and the information of someone they are caring for, such as a child or parent. PHRs are maintained and updated by consumers, capturing information from a health care provider and one's own personal records.⁴⁴ PHRs are gaining in popularity: numerous insurers have made PHR technology accessible to their members, federal legislation encouraging PHR use has been proposed, and the federal American Health Information Community (AHIC) lists PHR adoption among its charges.^{45,46} Consistent with efforts at the national level, the state should raise consumer awareness of PHRs as a mechanism to manage one's health and health care.⁴⁷

CHARGE 8: Identify specific legal actions required for the priorities recommended by the clinical work team, including: (a) Whether statutory/regulatory amendments are needed; and (b) Practical, non-technical strategies and solutions for developing electronic health data exchange that will ensure the secure and confidential transmission of personal and medical information.

8.1 Legal Actions to Support Clinical Priorities

A number of recommendations included in this report propose adjustments to current Wisconsin Statute:

- The Wisconsin legislature should amend Wisconsin law governing disclosure of health information to providers for treatment purposes to be consistent with HIPAA. (Charge #4)
- The Wisconsin legislature should review Wisconsin Statutes protecting patient rights and revise them as necessary to ensure that any provider or entity that provides unfair or inappropriately discriminatory treatment is subject to severe penalties. (Charge #4)

⁴³ This recommendation is informed by the Markle Foundation's Personal Health Technology Council "Consumer and Patient Principles for System Design." (10/05): http://www.markle.org/downloadable_assets/consumer_principles_101105.pdf (accessed 9/26/06).

⁴⁴ According to the American Health Information Management Association (AHIMA), a PHR is defined as: "a collection of important information about your health or the health of someone you're caring for, such as a parent or a child, that you actively maintain and update." For more information, see: http://www.myphr.com/your_record/index.asp (accessed 11/7/06).

⁴⁵ The Consumer Empowerment Workgroup of the American Health Information Community (AHIC) is charged with: "Mak[ing] recommendations to the Community to gain wide spread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumer-centered." http://www.hhs.gov/healthit/ahic/ce_main.html (accessed 11/7/06).

⁴⁶ For additional information, see Terri Yablonsky Stat, "Physicians urged to create PHRs: Major health insurers already are on board." Special to the Chicago Tribune. (10/31/06): <http://www.chicagotribune.com/features/lifestyle/health/chi-0610310195oct31.1.6613386.story?coll=chi-health-hed> (accessed 11/7/06).

⁴⁷ AHIMA provides one possible mechanism of raising awareness of PHRs through its 'MyPHR' web site and associated public education programs. Additional information is available online at: www.myphr.com (accessed 11/7/06).

- The Wisconsin legislature should review Wisconsin Statutes protecting patient rights and revise them as necessary to ensure that any provider or entity that deliberately or inadvertently mishandles, inappropriately shares, or inappropriately distributes personal health information is subject to severe penalties. Penalties should reflect the egregiousness of the act. (Charge #4)
- The Wisconsin legislature should amend law to support electronic reporting of health related data to statutorily identified entities. (Charge #5)

In addition, as noted under Charge #2, the Consumer Interests Workgroup considered the Patient Care Workgroup's priority elements for data exchange in relation to existing protections under current law; numerous data elements were identified as areas of privacy concern. Legal barriers to exchange will also be considered more fully as part of part of the Health Information Security and Privacy Collaboration (HISPC). Thus, as Wisconsin's eHealth Initiative moves forward towards exchange, it will be imperative to continue to address this charge.



Wisconsin is one of 33 states participating in a national effort to identify privacy and security policies and practices that may affect the electronic exchange of health information. The findings of this project will inform the U.S. Department of Health and Human Services' efforts to develop and refine the business case for establishing a national health information network.^{48,49} This project has four phases:

- Assessment of variations in organization-level business policies;
- Identification of state and federal laws that affect health information exchange in Wisconsin;
- Identification of practical solutions that protect the privacy and security of health information and permit interoperable health information exchange; and
- Development of plans to implement identified solutions.

The Consumer Interests Workgroup is charged with oversight of this project on behalf of the eHealth Board. Progress to date, and plans going forward, are outlined below.

9.1 Health Information Security and Privacy Collaboration (HISPC) Project

The first two phases of the HISPC project are complete. Two volunteer workgroups, *Variations* and *Legal*, reviewed 18 scenarios designed by RTI and highlighted potential procedural and legal challenges related to health information exchange. A number of Consumer Interests Workgroup

⁴⁸ For additional information on the goals of this project as they pertain to a national health information network, see: http://healthit.ahrq.gov/portal/server.pt?open=514&objID=5562&mode=2&holderDisplayURL=http://prodportalb.ahrq.gov:7087/publishedcontent/publish/communities/a_e/ahrq_funded_projects/rti_public_page/main.html (accessed 11/7/06).

⁴⁹ For additional information on Wisconsin's activities under the HISPC project, see the eHealth Board web site: <http://ehealthboard.dhfs.wisconsin.gov/security/> (accessed 11/7/06).

members were active participants in both the Variations and Legal workgroups. In addition, each workgroup was chaired by a member of the Consumer Interests Workgroup.

Consumer Interests Workgroup members will continue to play an active role in the Solutions and Implementation phases of the HISPC project. All participating members of the Consumer Interests Workgroup have been invited to serve on the Solutions Workgroup, and many are expected to continue through to the Implementation Workgroup.

NEXT STEPS

The Consumer Interests Workgroup has made significant progress towards each of its charges and has begun to dialogue with individual Wisconsin consumers and consumer groups. As Wisconsin advances towards adoption and implementation of interoperable electronic health records, it will be crucial for the eHealth Board to continue engaging consumers and their advocates in constructive, open discussions. The following activities should also be high priorities for the eHealth Board in the next stages of Wisconsin's eHealth Initiative:

1. Define specific recommended guidelines and real-world examples that clarify how data sharing can balance the requirement to protect patient privacy and system security with the need to share information to improve patient-centered care.
2. Develop recommendations for actions that will prevent breaches of privacy, security, or confidentiality of patient health information, within organizations and in the exchange of information among organizational systems, as well as remedies for any breaches that occur.
3. Develop specific mechanisms to accommodate patient concerns and complaints related to health information exchange.
4. Build understanding of, and support for, health information exchange among consumers and health care providers through education efforts.
5. Guide implementation of the consumer interests and privacy components of the eHealth Action Plan; assess and report on progress annually.
6. Develop policy statements and recommendations regarding use of health information for purposes other than treatment (e.g., patient safety initiatives, quality improvement, health care operations, payment, law enforcement, etc.).
7. Develop policy statements and recommendations that empower consumers to manage their health, health care, and health information.
8. Oversee preparation of final reports for the Health Information Security and Privacy Project.

APPENDICES

Appendix A: Disclosure of Health Information in Wisconsin - treatment

		Information to health care providers (as defined by Wisconsin law) for treatment purposes	
		Regulation Influences (State/Fed)	Treatment Under Controlling Law
Type of health information	General Information	§146.81-.84, Wis. Stats; §146.50, Wis. Stats.; HIPAA	Disclose without patient consent.
	Mental Health	§51.30, Wis. Stats.; HFS 92; Wis. Admin. Code; HIPAA (psychotherapy notes only as defined by HIPAA)	Disclose with patient consent with the following exceptions: (1) in a treatment emergency, limited to the part of the records necessary to meet the medical emergency [51.30(4)(b)8.] (2) within a mental health treatment facility while the patient is still an inpatient on need-to- know basis [51.30(4)(b)6.]; (3) exchange of limited information among providers within a related health care entity [51.30(4)(b)8g.] Psychotherapy notes as defined by HIPAA - disclose with patient consent only.
	Alcohol/Drug Abuse Treatment	§51.30, Wis. Stats.; HFS 92; Wis. Admin. Code; 42 CFR part 2; HIPAA	Disclose with patient consent. 42 CFR: Disclose without patient consent to medical personnel for the purpose of treating a medical condition that poses an immediate threat to the health of any individual and which requires immediate medical intervention [42 CFR 2.51(a)].
	Developmental Disabilities	§51.30; Wis. Stats; HFS 92, Wis. Admin. Code; HIPAA	Disclose with patient consent, except: (1) in treatment emergency limited to the part of the records necessary to meet the medical emergency [51.30(4)(b)8.] and within a developmental disability treatment facility while the patient is still an inpatient on need to know basis [51.30(4)(b)6.]; (2) exchange of limited information among providers within a related health care entity [51.30(4)(b)8g.]
	Communicable Disease	§146; 51.30, Wis. Stats.; §252.11, Wis. Stats; HFS 145; HIPAA	146: Disclose without patient consent. For Public Health Reporting see Appendix F. 51.30: Disclose without consent while inpatient or in medical emergency otherwise consent is required.
	HIV Test Results	§252.15, Wis. Stats (HIV Test Results); HIPAA (no specific reference to HIV test results)	Disclose without patient consent.
	Genetic Testing		No federal or state protection except for information to insurers. Federal legislation pending.
	Adoption	§48.432-.433, Wis. Stats.; HIPAA	Records of adoptive child (may extend to relevant information of natural parents) prior to adoption are not available post adoption – even with patient/legal guardian consent. Post-adoption: follow 146: Disclose without patient consent. Requires court intervention to provide this information to a provider for treatment from pre-adoption records. Pre-adoption records are provided to the agency facilitating the adoption and managed and/or accessed by legal processes (State of Wisconsin Adoption Records Search Program).
	Sexual Assault	§146.81-.84, Wis. Stats; §51.30, Wis. Stats; HFS 92, Wis. Admin. Code; HIPAA *	Disclose without patient consent. If 51.30 applies – follow 51.30.
	Domestic Violence	§146.81-.84, Wis. Stats.; §51.30, Wis. Stats; HFS 92, Wis. Admin. Code; HIPAA *	Disclose without patient consent. If 51.30 applies – follow 51.30.

* Separate Statutes regulate the disclosure of information in a record created and held by a domestic violence or sexual assault service agency.

Appendix B: A Comparison of Wisconsin Law and HIPAA for Treatment Purposes

Chapter 51: State Alcohol, Drug Abuse, Developmental Disabilities, and Mental Health Act

Section 51.30, Wis. Stats., further supported by HFS 92, Wis. Admin. Code, and 42 CFR Part 2, establishes protections for the confidentiality and disclosure of treatment records for patients provided AODA, developmental disability, and/or mental health services in treatment facilities. Special protections, exceeding those set forth in Wisconsin Statutes 146.81-.84, are provided to treatment records with regard to external disclosure. As noted below, state regulation imposes more stringent standards than the federal HIPAA Privacy Rule disclosure standards with respect to the privacy of the health information.

Under §51.30, patient treatment records may not be disclosed to healthcare providers for treatment purposes without patient informed consent, except in rare circumstances (e.g., treatment emergency, immediate threat requiring medical intervention, and among treating network providers). Treatment records may be disclosed for required public health reporting purposes. With appropriate administrative processes and approvals (DHFS, Institutional Review/Privacy Boards), treatment records may be disclosed for research purposes.

‘Treatment records’ include the registration and all other records that are created in the course of providing services to individuals for mental illness, developmental disabilities, alcoholism, or drug dependence and that are maintained by treatment facilities.⁵⁰

An ‘informed consent’ for disclosure of information from treatment records to an individual, agency, or organization must be in writing and must contain the following: the name of the individual, agency, or organization to which the disclosure is to be made; the name of the subject individual whose treatment record is being disclosed; the purpose or need for the disclosure; the specific type of information to be disclosed; the time period during which the consent is effective; the date on which the consent is signed; and the signature of the individual or person legally authorized to give consent for the individual.⁵¹

Key Differences Between §51.30 and HIPAA

HIPAA allows for disclosure of patient personal health information (PHI) without a patient authorization for treatment purposes whereas §51.30, Wis. Stats, requires an informed consent/authorization with the following exceptions:

1. A treatment emergency;
2. Within a mental health or developmental disability treatment facility while the patient is still an inpatient on a need-to-know basis; and
3. The exchange of limited of health information among providers in a related health care entity.

For a more detailed analysis of requirements by diagnosis and disclosure type, refer to Appendices A and F.

⁵⁰ § 51.30(1)(b), Wis. Stats.

⁵¹ § 51.30(2), Wis. Stats.

Appendix C: Health Care Providers

‘Health care providers’ refers to members of the following professions licensed or certified under Wisconsin law, §146.81, Wis. Stats.:

1. Nurse
2. Chiropractor
3. Dentist
4. Physician, physician assistant, perfusionist, or respiratory care practitioner
5. Physical therapist
6. Podiatrist
7. Dietitian
8. Athletic trainer
9. Occupational therapist or occupational therapy assistant
10. Optometrist
11. Pharmacist
12. Acupuncturist
13. Psychologist licensed
14. Social worker, marriage and family therapist, or professional counselor
15. Speech-language pathologist or audiologist
16. Massage therapist or bodyworker
17. Partnership of any providers specified under pars. (a) To (hp).
18. Corporation or limited liability company of any providers specified under pars. (a) to (hp) that provides health care services.
19. Operational cooperative sickness care plan organized under ss. 185.981 to 185.985 that directly provides services through salaried employees in its own facility.
20. Hospice licensed under subch. IV of chi. 50.
21. Inpatient health care facility, as defined in s. 50.135
22. Community-based residential facility, as defined in s. 50.01 (1g).
23. Rural medical center, as defined in s. 50.50 (11).

Appendix D: Mandatory and Discretionary Reporting Requirements – Public Health

While the lists below provide many examples of mandatory and discretionary reporting requirements in Wisconsin, they are not an exhaustive list of these requirements.

Public Health Mandatory Reporting

Under Wisconsin law, providers must report the events, diseases, and situations listed below to the Wisconsin Department of Health and Family Services:

1. Deaths: Unusual circumstances, homicides, suicides, following an abortion, caused by poisoning, following accidents, no physician in attendance prior to 30 days, physician refuses to sign death certificate, when physician unavailable to sign death certificate (§979.01, Wis. Stats.)
2. Deaths due to suicide, seclusion/restraint use or psychotropic medications in mental health programs, nursing homes, and community based residential facilities. (§51.64, 50.04(2t), 50.035(5), Wis. Stats)
3. Births: Birth and Developmental Abnormalities (§253.12, Wis. Stats.)
4. Induced Abortions (§69.186, Wis. Stats.)
5. Non-spousal Artificial Insemination: Husband's consent (§891.40, Wis. Stats.)
6. Lead Poisoning: Requires reporting of diagnosis of lead poisoning or lead exposure, including any lead screening, regardless of result (§254.13(1), Wis. Stats)
7. Communicable Diseases: *Category I:* Anthrax, Botulism, Botulism, infant, Cholera, Diphtheria, Food-borne or water borne outbreaks, Haemophilus influenzae invasive disease, Hantavirus infection, Hepatitis, viral type A, Hepatitis E, Measles, Meningococcal disease, Pertussis, Plague, Poliomyelitis, Rabies (Human), Ricin toxin, Rubella (congenital syndrome), Smallpox, Tuberculosis, Yellow Fever

Category II: Amebiasis, Arboviral infection (encephalitis/meningitis), Babesiosis, Brucellosis, Campylobacteriosis (campylobacter infection, Cat scratch disease, Cryptosporiasis, Cyclosporiasis, ehrlichiosis, Encephalitis, viral (other than arboviral, E-coli and other enterohemorrhagic E-coli, Giardiasis, Hemolytic uremic syndrome, Hepatitis, viral types B, C, D, non-A, non-B (acute), Histoplasmosis, Kawasaki disease, Legionnaires' disease. Leprosy, Leptospirosis, Listeriosis, Lyme disease, Malaria, Meningitis, viral, Meningitis, bacterial, Mumps, Nontuberculous mycobacterial disease, Psittacosis, Q fever, Reye's syndrome, Rheumatic fever, Rocky mountain spotted fever, Salmonellosis, Sexually transmitted diseases, Shigellosis, Streptococcal disease, streptococcus pneumoniae invasive disease, Tetanus, Toxic shock syndrome, Toxic substance related disease, Toxoplasmosis, Trichinosis, Tularemia, Typhoid fever, Typhus fever, Varicella, Yersiniosis, suspected outbreaks of other acute or occupationally related diseases

Category III: Acquired immune deficiency syndrome (AIDS), Human Immunodeficiency virus (HIV) infection, CD4+T-lymphocyte count

8. Sexually Transmitted Diseases (see number 6 above)

9. Child Abuse (§48.981, Wis. Stats.)
10. Cancer (§255.04, Wis. Stats.)
11. Infant Drug or Alcohol Screens (§146.0255, Wis. Stats.)
12. Crime injuries, Gunshot wounds, Burns (§146.995, 146.995(2)(a)3, Wis. Stats.)
13. Caregiver abuse (§146.40(4r), Wis. Stats.)
14. Certain limited situations of abuse, neglect, financial exploitation and self-neglect of adults at risk (§46.90, 55.043, Wis. Stats.)
15. Caregiver Misconduct (HFS ch. 13, Wis. Admin. Code)

Public Health Discretionary Reporting

Under Wisconsin law, providers may choose to report the following events, diseases, and situations, to the Wisconsin Department of Health and Family Services:

1. Unsafe Drivers (§146.82(3)(a), Wis. Stats.)
2. Abuse, Neglect, Financial Exploitation and Self-Neglect of Most Adults at Risk (§46.90 and 55.043, Wis. Stats.)

Appendix E: Public Health Surveillance Authority

Under Wisconsin law, designated public health entities may:

1. Investigate the cause and circumstances of any special or unusual disease or mortality (§250.04(1), Wis. Stats.)
2. Establish Surveillance Systems to detect any occurrence of acute, communicable or chronic diseases and threat of occupational or environmental hazards, injuries or changes in the health of mothers and children. (§250.04(3)(a), Wis. Stats.)
3. Analyze occurrences, trends and patterns of acute, communicable or chronic diseases, maternal and child health, injuries and occupational and environmental hazards and distribute information based on the analyses. (§250.04(3)(b)(1), Wis. Stats.).
4. Operate a Public Health Data System (§250.04(3)2), Wis. Stats.)
5. Conduct investigations, studies, experiments and research pertaining to any public health problems which are a cause or potential cause of morbidity or mortality. Individual questionnaires or surveys shall be treated as confidential patient health care records under §146.81 to 146.835, but the information in those questionnaires and surveys may be released in statistical summaries. (§250.04(3)(b)(3), Wis. Stats.)
6. Use hospital emergency room and inpatient health care records, abstracts of these records and information the state or federal government collects to correlate exposure to certain occupational and high risk environments with resulting acute or chronic health problems. (§250.04(3)(b)(4), Wis. Stats.)

Appendix F: Disclosure of Health Information in Wisconsin - public health

Type of health information	Information to state and local public health department for surveillance and epidemiology purposes		
	Regulation Influences (State/Fed)		For Reporting, Epidemiology, Surveillance, Etc. (If Public Health Department is providing treatment, refer to “A. Treatment”)
	General Information	§146.82 (2)(a) 5, Wis. Stats.; Various Wisconsin Reporting Statutes (see Appendix A); HIPAA	For required reporting disclose without patient consent. For disclosure of information beyond required reporting – disclose without patient consent to legally authorized state agency.
	Mental Health	§51.30(4)(b) 1, Wis. Stats.; Various Wisconsin Reporting Statutes (see Appendix A); HIPAA	For required reporting disclose without patient consent. For exchange of information beyond required reporting, disclose without patient consent to agency designated by DHFS with written documentation of authority for access per statute or authority of DHFS. Any other information, disclose with patient consent only.
	Alcohol/Drug Abuse Treatment	§51.30(4)(b)1, Wis. Stats.; Various Wisconsin Reporting Statutes (see Appendix A); HIPAA 42 CFR 2.53	For required reporting disclose without patient consent. For exchange of information beyond required reporting - disclose without patient consent to agency designated by DHFS with written documentation of authority for access per statute or authority of DHFS. Any other information – disclose with patient consent only. If disclosure does not identify the patient as receiving alcohol and/or drug abuse, the communicable disease information may be reported to the appropriate state agency. Also, in the event that a public health investigation may be deemed a health oversight agency activity, limited information with documented assurance regarding patient privacy may be accessible.
	Developmental Disabilities	§51.30(4)(b)1, Wis. Stats.; Various Wisconsin Reporting Statutes (see Appendix A); HIPAA	For required reporting disclose without patient consent. For exchange of information beyond required reporting - disclose without patient consent to agency designated by DHFS with written documentation of authority for access per statute or authority of DHFS. Any other information – disclose with patient consent only.
	Communicable Disease See Appendix A	Various Wisconsin Reporting Statutes (see Appendix A); §146.82(2)(a)5., Wis. Stats.; §51.30(4)(b)1., Wis. Stats.; §252.15(5)(a)6, Wis. Stats.; HIPAA	Disclose without patient consent for legally required reporting. [146. 51.30. 252.15]. For additional access: For 146: disclose without patient consent to legally authorized state agency [146.82(2) (a) 5.]. For 51.30: disclose without patient consent to agency designated by DHFS with written documentation of authority for access per statute or authority of DHFS. For 252.15: disclose without patient consent to the state epidemiologist or designee for the purpose of providing epidemiologic surveillance or investigation or control of communicable disease.
	HIV Test Results	§252.15(5)(a)6, Wis. Stats.; HIPAA	Disclose without patient consent to the state epidemiologist or designee for the purpose of providing epidemiologic surveillance or investigation or control of communicable disease.
	Genetic Testing	§146.82(2)(a)5, Wis. Stats; Various Wisconsin Reporting Statutes (see Appendix A); HIPAA	Disclose without patient consent for legally required reporting. For additional exchange of information – see “General Information, Mental Health, Alcohol/Drug Abuse and Developmental Disability” categories. No specific state or federal law protection. Federal law pending.
	Adoption	Various Wisconsin Reporting Statutes (see Appendix A); HIPAA	Disclose without patient consent for legally required reporting. For additional exchange of information – see “General Information, Mental Health, Alcohol/Drug Abuse and Developmental Disability” categories.
	Sexual Assault	§146.82(2)(a)5, Wis. Stats.; Various Wisconsin Reporting Statutes (see Appendix A); HIPAA*	Disclose without patient consent for legally required reporting. For additional exchange of information – see “General Information, Mental Health, Alcohol/Drug Abuse and Developmental Disability” categories.
	Domestic Violence	§146.82(2)(a)5, Wis. Stats.; Various Wisconsin Reporting Statutes (see Appendix A); HIPAA*	Disclose without patient consent for legally required reporting. For additional exchange of information – see “General Information, Mental Health, Alcohol/Drug Abuse and Developmental Disability” categories.

* Separate Statutes regulate the disclosure of information in a record created and held by a domestic violence or sexual assault service agency.

Appendix G: Disclosure of Health Information in Wisconsin - research

Type of health information	Information to external or internal researchers		
	Regulation Influences (State/Fed)		For Research
	General Information	§146.82(2)(a)6, Wis. Stats.; HIPAA 164.512(i)	Disclose without patient consent upon documentation of the following – Waiver received from the Institutional Review Board (IRB) or Privacy Board and affiliation between the researcher and the healthcare provider (affiliation not defined) and privacy assurances from the researcher.
	Mental Health	§51.30(4)(b)3, Wis. Stats.; HIPAA 164.512(i)	Disclose without patient consent upon documentation of the following - Waiver received from the Institutional Review Board (IRB) or Privacy Board, approval by DHFS and assurances from the researcher relating to patient privacy.
	Alcohol/Drug Abuse Treatment	§51.30(4)(b)3, Wis. Stats.; HIPAA 164.512(i); 42 CFR 2.52	Disclose without patient consent upon documentation of the following - Waiver received from the Institutional Review Board (IRB) or Privacy Board, approval by DHFS and assurances from the researcher relating to protocols, patient privacy, 3 person independent review and no redisclosure of identifying information (other than to program).
	Developmental Disabilities	§51.30(4)(b)3, Wis. Stats.; HIPAA 164.512(i)	Disclose without patient consent upon documentation of the following - Waiver received from the Institutional Review Board (IRB) or Privacy Board, approval by DHFS and assurances from the researcher relating to patient privacy.
	Communicable Disease *	§146.82(2)(a)6, Wis. Stats.; HIPAA 164.512(i)	Disclose without patient consent upon documentation of the following – Waiver received from the Institutional Review Board (IRB) or Privacy Board and affiliation between the researcher and the healthcare provider (affiliation not defined) and privacy assurances from the researcher.
	HIV Test Results	§252.15(5)(a)10, Wis. Stats.; HIPAA 164.512(i)	Disclose without patient consent upon documentation of the following – Waiver received from the Institutional Review Board (IRB) or Privacy Board and affiliation between the researcher and the healthcare provider (affiliation not defined) and written privacy assurances from the researcher.
	Genetic Testing	§146.82(2)(a)6, Wis. Stats.; HIPAA 164.512(i)	Disclose without patient consent upon documentation of the following – Waiver received from the Institutional Review Board (IRB) or Privacy Board and affiliation between the researcher and the healthcare provider (affiliation not defined) and privacy assurances from the researcher. No specific state or federal protection. Federal law pending.
	Adoption	§146.82(2)(a)6, Wis. Stats.; HIPAA 164.512(i)	Disclose without patient consent upon documentation of the following – Waiver received from the Institutional Review Board (IRB) or Privacy Board and affiliation between the researcher and the healthcare provider (affiliation not defined) and privacy assurances from the researcher. May need further research on pre-adoption records.
	Sexual Assault	§146.82(2)(a)6, Wis. Stats.; HIPAA 164.512(i) *	Disclose without patient consent upon documentation of the following – Waiver received from the Institutional Review Board (IRB) or Privacy Board and affiliation between the researcher and the healthcare provider (affiliation not defined) and privacy assurances from the researcher.
	Domestic Violence	§146.82(2)(a)6, Wis. Stats.; HIPAA 164.512(i) *	Disclose without patient consent upon documentation of the following – Waiver received from the Institutional Review Board (IRB) or Privacy Board and affiliation between the researcher and the healthcare provider (affiliation not defined) and privacy assurances from the researcher.

* Separate Statutes regulate the disclosure of information in a record created and held by a domestic violence or sexual assault service agency.